

Fact Sheet on Programmatic Example

(Note: this is just an example of the type of evidenced based or promising practice that may implement all or part of a BSK strategy.)

Strategy to be Addressed:

Build resiliency of youth and reduce risky-behaviors

Program Name:

Early Detection and Intervention for the Prevention of Psychosis Program (EDIPPP)

Brief Program Description:

The program targets adolescents and young adults at risk for a psychotic incident. The program has a strong outreach component in which key individuals throughout communities who interact regularly with young people are educated to understand and recognize symptoms of psychosis, and to refer young people identified with risk symptoms for an assessment. The assessment is used to determine referrals to clinical treatment using a skill building intervention and family aided assertive community treatment model. Outreach materials include printed educational materials, website information and video. Families in clinical treatment are offered the following interventions, depending on need: Case management, supportive counseling, multi-family group therapy, supported education and employment, and medication management.

Prevention Results Achieved Elsewhere or in K.C. Pilot:

Results are from five pilot sites in the U.S., as follows: 1) Skill building family-aided assertive community treatment was effective in managing positive symptoms; 2) Negative symptoms decreased; 3) Rates of conversion to psychosis were even lower than expected; 4) Early findings suggest that rates of hospitalization for psychotic episodes were down in all pilot sites; 5) In the group receiving education and employment supports as part of the treatment, participation in work or school remained steady, but such participation fell in the control group that did not receive such supports.

Target Population and number of people served:

The target population is adolescents and young adults in general, in order to identify those at risk for a psychotic incident. A broad base of persons in the community that interact with young people are also targeted for training and education in order to identify and refer young people showing early signs of risk for psychosis to further assessment and then to treatment, if

warranted. For a population the size of King County, it is estimated that over a two-year period approximately 400 outreach activities would reach 20,000 people that interact with young people; approximately 800 young people will be referred for assessment, and between 50% and 75% of those 800 young people and their families will receive family-aided assertive community treatment.

Estimated Cost to Administer:

Approximately \$2 million per year across King County

Estimated Cost Savings to Community:

One very rough estimate of fiscal cost savings are extrapolated from potential reductions in hospital admissions for psychotic incidents (reductions in the study areas range from 26% to 34%); savings from reduced hospital admissions for psychotic incidents in young people under the age of 30 might be in the ballpark of \$2.1 million annually¹. Significant savings are also anticipated to be realized through less need for expensive anti-psychotic medications, fewer negative health consequences, fewer negative life consequences that can lead to need for expensive crisis services, reduced instability in school and employment settings and safer communities.

¹ This is a very rough estimate of reduced costs in hospital admissions using MHCADSD and CHARS data, and is currently missing Western State Hospital data, which can be added at a later date.

Early Detection and Intervention for the Prevention of Psychosis in Adolescents and Young Adults

An RWJF national program replicates the Portland Identification and Early Referral (PIER) Program

SUMMARY

The *Early Detection and Intervention for the Prevention of Psychosis Program* (EDIPPP)¹ helps to identify and curb acute psychotic illness before it begins. Targeted at young people, the \$16.9 million national program of the Robert Wood Johnson Foundation (RWJF) combines community outreach, research, and treatment, and emphasizes family involvement and strategies for recognizing at-risk individuals.

CONTEXT

Going off to college can be a stressful. That's how 17-year Tiffany Martinez explained it to herself when, as a freshman at the University of Southern Maine, she began to hear voices, see shadowy figures, and have troubling, intrusive thoughts.

"I would walk out into the courtyard outside my dorm," Martinez recalled. "And for some reason I had this thought to be careful of the trees because they were going to collapse on me."

Her friends finally convinced Martinez to go to the university health center where she met with a nurse who had just attended a seminar to educate staff on mental illness in young adults. The nurse suspected Martinez was showing early, or prodromal, signs of psychosis and referred her to the Portland Identification and Early Referral (PIER) program at the Maine Medical Center, which provides a comprehensive program of treatment, counseling, and psychoeducational support that aims to prevent psychosis before it becomes full blown.

¹ RWJF's title for this program is *National Demonstration of Early Detection, Intervention and Prevention of Psychosis in Adolescents and Young Adults*. That is the name that appears on the RWJF website. In the field, the program is known by the title used in this report.

Tiffany Martinez is featured in a video, "Preventing the Onset of Severe Mental Illness: Lessons Learned," available online. Read her full story in a sidebar at the end of this report.

Even clinicians who have been in practice for a long time often do not connect symptoms such as those that Martinez was experiencing to psychosis, said Sarah Lynch, MSW, of EDIPPP. "Honestly, if you are looking at the clinical picture in one way, you may not see prodromal symptoms," she said. "Unless you really understand the subtlety of how they begin, you can miss it."

Early symptoms may include hallucinations—seeing or hearing things that are not there—or delusions—persistent thoughts that do not go away after receiving logical or accurate information. But those with early symptoms may also display other cognitive and sensory changes—not being able to think straight, focus, or speak coherently, and being overly sensitive to sensory input. The symptoms often are attributed to an array of other problems besides psychosis, such as attention deficit disorder, anxiety, or lack of sleep.

Psychotic disorders most often first appear when a person is in his or her late teens, 20s, or 30s, and tend to affect men and women about equally.² Psychotic illnesses exact a tremendous cost to individuals, as well as to their families and communities. Among the costs are lost productivity, increased family stress; increased physical illnesses; diminished self-esteem; increased dependency; repeated need for hospitalizations; inability to maintain friendships; and difficulty attaining life goals, such as completing school and working.

Some typical and early warning signs of psychosis include:

- Worrisome drop in grades or job performance
- New trouble thinking clearly or concentrating
- Onset of suspiciousness/uneasiness with others
- Decline in self-care or personal hygiene
- Spending a lot more time alone than usual
- Increased sensitivity to sights or sounds
- Mistaking noises for voices
- Unusual or overly intense new ideas
- Strange new feelings or having no feelings at all

Source: National Alliance on Mental Illness

² A wide variety of central nervous system diseases, from both external substances and internal physiologic illness, can produce symptoms of psychosis. These diseases include schizophrenia, schizophreniform disorder, schizoaffective disorder, delusional disorder, brief psychotic disorder, bipolar disorder, and major depression with psychotic features. Substance use (including intoxication or withdrawal from alcohol, street drugs, or prescription medications) and medical conditions (such as infection, epilepsy, head injury, cancer, or autoimmune disorders) can also cause psychosis.

Some estimate the cost to society exceeds \$10 million over the course of an individual's lifetime, especially if the diagnosis is schizophrenia.

Can Psychosis Be Prevented?

Until the early 1980s, it was assumed that people with symptoms like those Martinez was experiencing would eventually progress to a full psychotic illness. The symptoms could be treated, but the illness could not be prevented. William R. McFarlane, MD, director of the PIER program and the Center for Psychiatric Research at Maine Medical Center, is one of a group of clinicians and researchers worldwide that has challenged that conventional wisdom.

"When you develop schizophrenia, you drive off a cliff," McFarlane says. "So imagine you could stop the process already underway. You're driving down the road toward a psychotic episode and you either drive off the cliff or you don't."

McFarlane cites early studies that laid the groundwork for a different kind of approach to psychotic illness. Michael Goldstein, PhD, and colleagues at UCLA found that adolescents who developed schizophrenia and related disorders in adulthood were most often from families that, at baseline, had shown high levels of "communication deviance" (unclear, unintelligible, or fragmented communication) or negative "affective style" (parent-to-offspring communication that is strongly evaluative, critical, or intrusive).

While this research was controversial—it could be seen as blaming the family for an individual's illness—it opened up the possibility that a change in family dynamics might have an impact on the progression of an individual's psychotic illness. Out of the research grew an intervention called family psychoeducation, which emphasizes educating families about how symptoms may unfold and how to respond.

"You need to be educated to empower yourself, or, if you are a parent, to empower your child to take control of this illness process," said Jane Lowe, PhD, senior adviser for program development at RWJF. "There is a powerful connection here to being an informed and competent consumer."

In collaboration with researchers in Norway, McFarlane developed an adaptation of multifamily psychoeducational intervention. Working in groups, people with prodromal symptoms and their families come together to problem solve, practice communication skills, and learn strategies for coping with symptoms.

A key challenge with the intervention was identifying people with early symptoms well before they landed in the emergency room with a first episode of psychosis. "If you want to identify someone at risk...then you would be talking with and educating the people who spend a lot of time with adolescents," McFarlane said. "You don't need to be a scientist to figure that out. That would be people who work in schools, colleges,

universities, military, clergy, athletics, as well as mental health practitioners, agencies, and hospitals.”

Creating the PIER Program

In 1999, McFarlane combined several elements of the programs developed in the United States and abroad to create the Portland Identification and Early Referral (PIER) program. The goal was to identify young people in the Greater Portland, Maine, area between the ages of 12 and 25 who might be at risk for psychosis, and then to offer appropriate treatment.

Starting in December 2000, the multidisciplinary PIER team began educating community stakeholders outside the mental health system, including primary care physicians, school nurses, and counselors about the early signs of psychosis. The intent was to build a network of community members who would be equipped to recognize young people at risk and refer them to PIER.

Youth admitted to the PIER program were offered intensive treatment and rehabilitation in partnership with their families aimed at preventing the onset of a full-blown illness.

Enter RWJF

In 2002, RWJF provided funding through its *Robert Wood Johnson Foundation Local Funding Partnerships* program to develop the PIER model further.³ Early results, published in an article in *Psychiatric Services*, were promising: PIER’s first six years showed a 26 percent drop in first psychiatric hospitalizations for psychotic disorders in the Greater Portland catchment area compared to an 8 percent rise in the aggregated urban areas in Maine that served as the control. The net result was a 34 percent decrease from the expected rate.⁴

Statewide, some 30 to 40 percent of young people exhibiting early symptoms go on to have a full-blown diagnosable illness, but fewer than 15 percent of cases treated by PIER had deteriorated to a psychotic symptom level. Most of the others had responded to aggressive treatment with a decrease or even a disappearance of earlier symptoms,

³ RWJF’s Grant ID# 46139 (\$500,000, August 1, 2002 to July 31, 2007) provided initial funding. The Center for Mental Health Services at the Substance Abuse and Mental Health Services Administration provided funds for community outreach beginning in 2001. In 2003, the National Institute of Mental Health funded a randomized trial comparing the PIER treatment protocol with an attenuated version that did not include the intensity of interventions.

⁴ McFarlane WR, Susser E, McCleary R, Verdi M, Lynch S, Williams D, and McKeague IW. “Reduction in Incidence of Hospitalizations for Psychotic Episodes Through Early Identification and Intervention.” *Psychiatric Services*. March 17, 2014. Available online.

usually with a return to school or to a higher level of functioning than before entering the program.⁵

“What we learned from that project was that these kids were not hard to identify,” said RWJF’s Lowe, who oversaw the program and the early grants made through the *RWJF Local Initiative Funding Partners program*.

“Almost every teacher, school counselor, or school social worker knew. Or the pediatrician knew. These are the kids that are excelling and then suddenly taking a nosedive—being isolated, withdrawn, not doing well in school.... It became very clear you could train people to identify these young people correctly.”—Jane Lowe, RWJF

RWJF wanted to test whether the PIER model of outreach and early identification would work in other communities, particularly ones more diverse than the relatively homogeneous Portland, Maine, community.

In 2006, RWJF established the *Early Detection and Intervention for the Prevention of Psychosis Program (EDIPPP)*, the national program that is the subject of this report, to oversee replication of the PIER program at five additional sites across the United States.

RWJF’s Interest in This Area

The Foundation’s earliest work in mental health focused on integrating services into the community support system. According to a chapter in the Robert Wood Johnson Foundation Anthology (2000):⁶

After a period of analysis from 1984 to 1986, the Foundation concluded that the problem of mental health services was a systems problem, requiring intervention in the organization and financing of services. It developed a series of three initiatives: the Mental Health Services Development Program, the Mental Health Services Program for Youth,⁷ and the Program on Chronic Mental Illness, the biggest of the three. All began in the late 1980s and continued into the 1990s.

Although the Foundation’s activity in mental health slowed in the mid-1990s, the impact of these three initiatives was felt throughout the mental health services field,

⁵ Maier J. “Stopping Psychosis Before It Starts.” *Behavioral Healthcare*, October 31, 2007. Available online.

⁶ Goldman HH. “The Program on Chronic Mental Illness.” in *The Robert Wood Johnson Foundation Anthology*. 2000. Princeton, NJ: Robert Wood Johnson Foundation, 2000. Available online.

⁷ See the RWJF Anthology chapter on this program (Saxe L and Cross TP, 1999) online. RWJF also funded a replication of this program. See the Program Results Report.

stimulating new research and new ways of looking at service systems. The initiatives also influenced federal and state mental health activities—especially a subsequent wave of demonstration research.

RWJF has also addressed mental illness in homeless persons, first through its *Health Care for the Homeless* program, and more recently through its support of the Corporation for Supportive Housing, which integrates mental health services with housing for chronically homeless adults. See Special Report, *More Than a Place to Live*, and the Progress Report on the Returning Home program, focused on former prisoners, many with serious mental illness.

With \$17.3 million in funding from RWJF—and with six participating sites across the nation—EDIPPP is the Foundation’s largest investment in mental health to date, and the first focused on prevention.

THE PROGRAM

The *Early Detection and Intervention for the Prevention of Psychosis Program* (EDIPPP) was a national demonstration designed to identify young people between the ages of 12 and 25 at risk for a psychotic episode, and to intervene early. It started in August 2006 and ran to May 2013.

“We are really redefining mental illness to include its onset stage the same way we have done with cancer and heart disease,” McFarlane says. “If someone has angina would you wait to provide services for their illness? No. Now we know that angina is the possible lead up, but not always, to a major heart attack. We will have to get there with mental illness.”

In order to prevent the development of a severe mental illness, the EDIPPP was designed to:

- Replicate the PIER program at selected sites around the country each with unique geographic, socio-cultural, and environmental characteristics and varied organizational affiliations
- Rapidly bring the benefits of preventing severe mental illness to those communities
- Expand and accelerate evidence for the value of the model, while confirming results in Maine
- Establish centers of expertise to aid further regional dissemination and implementation of the model

- Disseminate findings to stakeholders, including state mental health authorities, mental health professionals, communities, schools, health facilities, policy-makers, and insurers

The program had three components:

- *Community outreach*, focused on educating individuals who interact regularly with young people and may be in a position to observe prodromal symptoms. These include school employees, social workers, doctors, nurses, students, parents, clergy, and law enforcement personnel.
- *Research* in which a specialized multidisciplinary clinical team assessed referred individuals' risk for psychosis and functioning level, assigned them to one of three study groups based on their symptoms (lower risk, higher risk, or early in their first episode of psychosis⁸), and tracked their progress.
- *Clinical treatment* geared towards the needs of young adults (between the ages of 12 and 25) at risk for a psychotic episode. The clinical program included in-depth assessment, multifamily group therapy, supported employment and education, and medication, as needed.

Funding

RWJF provided \$17.3 million for the program from August 1, 2006 to June 6, 2014.

National Program Office

The Maine Medical Center served as the national program office for the demonstration, overseeing all six sites' adherence to the model. William McFarlane, MD, then director of the Center for Psychiatric Research at Maine Medical Center and Spring Harbor Hospital, and professor of psychiatry at Tufts University School of Medicine, was program director. William Cook, PhD, served as deputy director for research until March 2012.⁹

Sarah Lynch, MSW, served as deputy director of administration from 2011 to the close of EDIPPP in 2014. Earlier in the program, Anita Ruff, MPH, held that position, and Donna Downing, MS, served as deputy director of training.

Advisory Committees

RWJF and national program office staff identified experts in a variety of fields, including psychopharmacology, economics, community mental health, and child psychiatry, and

⁸ Defined as less than 30 days of psychotic symptoms.

⁹ With Cook's departure in March 2012, Bruce Levin, PhD, professor of biostatistics at Columbia University Mailman School of Public Health, worked under contract to complete the study.

invited them to join a scientific advisory committee to review the EDIPPP protocol and make recommendations about the study design. See Appendix 1 for the list of members.

The national advisory committee was created to review applications, participate in site visits, and make funding recommendations to RWJF and the national program office. Members represented academic, community, medical, and governmental mental health professionals. See Appendix 1 for the list of members.

The Program Sites

RWJF awarded grants of \$2 million apiece to five sites across the United States for the outreach and education component of the program. A sixth site, in New Mexico, joined the program in January 2008, but received no RWJF funds. (See Appendix 2 for a list of projects.) Here are brief descriptions:

Portland Identification and Early Referral (PIER) Program at Maine Medical Center, Portland, Maine

The PIER program serves a catchment area that includes Portland and 25 surrounding towns. The population of some 333,000 is relatively homogenous, with recent immigrants adding some cultural diversity. PIER participated in the program both as a demonstration site and as the national program office.

PIER staff was instrumental in developing a new outreach and research protocol for the program, as well as training the other EDIPPP sites on both the protocol and procedures.

Early Assessment and Support Team (EAST) at Mid-Valley Behavioral Care Network,¹⁰ Salem, Ore.

Since 2001, EAST has used evidence-based early intervention for psychotic illnesses as a standard practice. EAST serves an area in Northwestern Oregon of some 6,000 square miles, with a population of almost 632,000. Overall, the state is 82 percent White, 12 percent Hispanic, 4 percent Asian, and 2 percent Black. The counties range in size and population density from Marion County with 315,335 people (267 per square mile) to Tillamook County with 25,250 (23 per square mile).

Michigan Prevents Prodromal Progression (M3P) Program at Washtenaw Community Health Organization, Ypsilanti, Mich.

M3P provides assessment and services to young people between the ages of 12 and 15 to reduce the incidence of mental illness through early prevention and education. M3P serves Michigan's Washtenaw County, which covers nearly 800 square miles and has a

¹⁰ Mid-Valley Behavioral Care Network is a five-county intergovernmental organization in Oregon.

population of 345,000. Roughly 20 percent of the population represents communities of color.

Recognition and Prevention (RAP) Program at Zucker Hillside Hospital, Queens, N.Y.

RAP is an early mental health intervention and prevention research program that has been ongoing at Zucker Hillside Hospital since 1998. Before EIDPPP, RAP offered adolescents and young adults an opportunity to discuss their concerns about recent changes in thoughts, feelings, functioning, and behavior with mental health professionals. The hospital is an inpatient and outpatient behavioral health facility within the larger North Shore-Long Island Jewish Health System that serves densely populated areas of Queens and Long Island. The RAP site's catchment area of just 53 square miles includes zip codes in Nassau County (Long Island) and the borough of Queens (New York City) that together have a highly ethnically diverse population of almost 558,000.

Early Detection and Preventive Treatment (EDAPT) Clinic at University of California, Davis, Sacramento, Calif.

Cameron Carter, MD, a psychiatrist and mental health researcher, created the Early Diagnosis and Preventative Treatment clinic (EDAPT) at the University of California, Davis, in 2003. Its catchment area, the city of Sacramento, has a diverse population of 466,500, including a Hispanic or Latino population of 27 percent. It also has large populations of African Americans and Asian Pacific Islanders.

Before joining the study, the EDAPT clinic staff had prior research experience and had conducted some community outreach to identify clients who had a first episode of psychosis.

Early Assessment and Resource Linkage for Youth (EARLY) Program at University of New Mexico, Albuquerque, N.M.

EARLY, based at the University of New Mexico Department of Psychiatry's Center for Rural and Community Behavioral Health, is located in Bernalillo County. The program serves Albuquerque, the largest metropolitan area in New Mexico, as well as some agricultural communities. The total population of 662,564 is ethnically diverse with 48 percent identifying as Hispanic or Latino.

In his junior year in high school, Sam (not his real name) began to suffer from extreme insomnia and what he called "brain fog"—difficulty focusing and concentrating. Identified as being at high risk for psychosis, he entered into EARLY, the early

identification and intervention program at University of New Mexico.

"Gradually we started to see a change in Sam," his parents explained in an article in Adolescent Psychiatry.¹¹ "He became more social and verbal again...[Multifamily group] turned out to be a safe and structured environment for him.... [He] became more engaged with the other members. With the help of EARLY, he began to set goals, and started to achieve them."

Technical Assistance

Staff at the national program office provided an array of assistance to the program sites, including:

- **Training:** All sites received the same multiday training on conducting community outreach, research assessments, and clinical interventions. The sites also participated in monthly calls and videotaped their assessment interviews and their multifamily groups to ensure fidelity to the model.
- **Annual Meetings:** The program held annual meetings each year from 2007 to 2012 where site staff received further training and discussed research results, challenges, and strategies for publication and dissemination. The final national meeting in March 2013 focused on public policy issues related to providing support for early identification and prevention of psychosis.

Evaluation

RWJF contracted with the University of Southern Maine's Muskie School of Public Service to evaluate the community outreach efforts of EDIPPP.¹² Brenda Joly, PhD, MPH, led the evaluation team. Designed as a participatory process, the evaluation provided feedback to the sites and the national program office as it progressed.

The national program office contracted with PCE Systems in Farmington Hills, Mich., to support and maintain an online database to capture information across all sites and to generate timely reports. The evaluation team worked with the vendor to develop a data collection strategy and trained staff in its use.¹³

¹¹ Migliorati M, Salvador M, Spring-Nichols E, Lynch S, Sale T and Adelsheim S. "In the First Person: A Window into the Experience of Early Psychosis and Recovery." *Adolescent Psychiatry*. 2(2). 146–152. 2012.

¹² ID# 62200 (\$487,375. August 15, 2007 to August 31, 2011).

¹³ ID# 63692 (\$48,048. January 15, 2009 to November 30, 2011).

Over a four-year period, beginning in 2008, the evaluation team produced 13 cross-site and grantee-specific evaluation reports based on its assessment of these elements:

- Outreach efforts across all demonstration sites
- Contextual factors that may influence implementation
- Specific outcomes of outreach activities

The reports also detailed the evaluation framework and methodology and described the major data collection tools and limitations. The evaluators described their research design, with a special focus on lessons of interest to others evaluating community outreach efforts, in the *Journal of MultiDisciplinary Evaluation* (July 2012).¹⁴ See summary of lessons learned in Appendix 3.

Cynthia Wilcox, LCSW, a school social worker for many years, knew little about early signs of psychosis until she attended a PIER seminar in 2004. Armed with this new knowledge, she and her colleagues were able to refer appropriate students to the program.

Then in 2010, Wilcox and her husband received a call that parents fear: the dean of the college saying, "Come quickly. Your son is displaying bizarre, potentially dangerous behavior." In that moment, Wilcox went from being someone who referred students to services to a consumer of those services. Read her full story in a [sidebar](#) at the end of this report.

OVERALL PROGRAM RESULTS

Community Outreach

All six EDIPPP sites followed a stepwise approach to outreach, which included:

- Community mapping to identify the organizations and individuals who have regular contact with young people in the at-risk target group.
- Establishing a steering council of referral gatekeepers and key community members
- Developing and delivering outreach messages to specific target audiences

¹⁴ Joly BM, Williamson ME, Bernard NP, et al. "Evaluating Community Outreach Efforts: A Framework and Approach Based on a National Mental Health Demonstration Project." *Journal of MultiDisciplinary Evaluation*. 8(17): 46-56, 2012. Abstract available online.

- Conducting a formative evaluation of outreach efforts. Each site selected an outreach catchment area, defined by either zip codes or town boundaries, which together encompassed almost 3 million people.

Outreach audiences included professional staff at schools, universities, and military bases; health and mental health professionals; community groups; media; youth; businesses; and multicultural communities.

At each site, a member of the team spearheaded the outreach effort. The outreach coordinator developed outreach materials (brochures and PowerPoint presentations), identified outreach targets, scheduled presentations for staff, and tracked outreach efforts in the database.

All sites utilized the same website, which offered information on early warning signs, printable educational materials, and a video about the treatment model featuring families who had received treatment at the PIER program in Maine. The website is no longer active, but it received more than half a million hits from the time it launched as part of PIER in 2005 until the end of the program in 2013.

Community Outreach Findings

The evaluators and program staff reported findings from the community outreach effort in two journal articles,¹⁵ one paper under review at *Psychiatric Services* as of October 2014,¹⁶ and reports to RWJF.

- **Despite diverse demographic characteristics, organizational affiliations, and history of outreach, all EDIPPP sites generated a stream of appropriate referrals.** See Appendix 4 for “Characteristics of Referrers to the Program.”

Over the two-year outreach evaluation period, March 2008 to March 2010:

- Five of the EDIPPP sites¹⁷ completed 539 outreach activities that reached approximately 23,315 people, including educational, mental health, and medical providers.

¹⁵ Joly B, Bernard KP, Williamson ME and Mittal P. “Promoting Early Detection of Psychosis: The Role of Community Outreach.” *Journal of Public Mental Health*. 11(4): 195–208, 2012. Abstract available online.

Joly BM, Williamson ME, Bernard KP, Mittal P, and Pratt J. “Evaluating Community Outreach Efforts: A Framework and Approach Based on a National Mental Health Demonstration Project.” *Journal of MultiDisciplinary Evaluation*. 8(17): 46–56, January 2012. Available online.

¹⁶ Lynch S, McFarlane W, Joly B, Adelsheim S, et al. “The Early Detection for the Prevention of Psychosis Program: Community Outreach and Early Identification at Six Sites across the United States.” Under review at *Psychiatric Services*.

¹⁷ The New Mexico EARLY site was excluded from the quantitative evaluation because the program joined the study late and had limited capacity, but EARLY did participate in qualitative elements.

- A total of 1,221 young people were referred during the evaluation period. Approximately 29 percent of those referred were brought into EDIPPP sites for evaluation. The remaining 71 percent were referred elsewhere for appropriate intervention based on symptom presentation. See Appendix 5 for data on the five sites.

- The evaluation team concluded in a report to RWJF that community outreach could be an effective tool:

“Evidence from this evaluation demonstrates that outreach efforts can reach priority groups, shape perceptions and create local networks that may result in referrals for specialty programs and clinical research. Results also show that relatively brief community engagement efforts can significantly increase the knowledge and awareness of the public of complex mental health issues.”

The evaluation highlighted the importance of targeting groups likely to have contact with individuals who need prevention or treatment; developing consistent core messages to guide referrers in identifying at-risk individuals and making referrals; and ensuring the credibility of educators and trainers involved in outreach.

Missed Opportunity

The national program office and evaluation staff also noted a missed outreach opportunity. Although some of the sites were in ethnically diverse communities, only English speakers could participate in the treatment program. “We had a very extensive assessment protocol,” said EDIPPP’s Sarah Lynch. “We had to have the client and a family member proficient in English. So in some of the more diverse settings, we had to turn away people. We couldn’t do the assessment with translation. That was a barrier.”

“It might have been worthwhile to have explicitly funded a site or sites to adapt outreach materials and the EDIPPP program to these audiences,” the evaluators suggested.

Research Protocol

From October 2007 to June 2010, McFarlane led a study of the effectiveness of the intervention at the Division of Research, Department of Psychiatry, and the Maine Medical Center Research Institute.

Program staff at the sites generally screened referrals by phone. Those indicating early, or prodromal, symptoms of psychosis were invited into the office for an orientation to the study. More than 90 percent of those referred consented to be evaluated.

Program staff evaluated referred individuals for pre-psychosis symptoms using a tool known as the Structured Interview for Prodromal Syndromes (SIPS), a 19-item questionnaire designed to measure the severity of prodromal symptoms and changes over time.

Those meeting study criteria were assigned to one of three study groups based on their symptoms: clinically lower risk, clinically higher risk, or early in their first episode of psychosis. The lower-risk group served as the control, receiving whatever services their families were able to find for them in the community.¹⁸

"The psychoeducational part of this treatment protocol is so critical for people. What to expect, how their symptoms may unfold, what to do if you are the parent of that child, etc. That is a very powerful piece and you need to be educated to empower yourself, or if you are a parent, to empower your child to take control of this illness process."—Jane Isaacs Lowe, PhD, Senior Adviser for Program Development, RWJF

Some 337 young people, with a mean age of 16.6, were assigned to the treatment group (higher risk or early first-episode psychosis, 250 young people) or comparison group (lower risk, 87 young people).

Clinical staff at the sites assessed study participants over 24 months for positive, negative, disorganized, and general symptoms;¹⁹ SCID-IV diagnoses;²⁰ social and role functioning; substance abuse; family functioning; and neurocognitive status. The study also gathered data across the six sites on rates of first hospital admissions for the same age group five to seven years prior to the intervention and compared that to three years

¹⁸ This design has an ethical advantage compared to random assignment because youth in the control group received monthly monitoring through a phone assessment conducted by a care manager and could obtain treatment elsewhere in the community. If a patient in the control group demonstrated severe or psychotic symptoms, they were offered antipsychotic medication by the onsite EDIPPP psychiatrist.

¹⁹ Positive symptoms are an excess or distortion of the individual's normal functioning, such as hallucinations and delusions. Negative symptoms reflect a decrease or loss of normal functions and may include flattened affect, failure to experience or express pleasure, reduced speech, and lack of initiative. Disorganized symptoms include odd behavior or appearance, bizarre thinking, trouble with focus and attention, and impairment in personal hygiene. General symptoms include sleep disturbance, dysphoric mood, motor disturbance, and impaired tolerance to normal stress.

²⁰ SCID-IV—short for Structured Clinical Interview for DSM-IV Disorders—is a semi-structured interview for diagnosing a personality disorder—an enduring pattern of behavior, cognitions, and inner experience exhibited across many contexts that deviates markedly from those accepted by the individual's culture. These patterns are inflexible and are associated with significant distress or disability. DSM-IV refers to the *Diagnostic & Statistical Manual of Mental Disorders*, fourth edition.

after the intervention started. The staff also compared results to an adjacent control catchment area for both periods.²¹

Clinical Intervention Protocol

Each of the EDIPPP sites had a multidisciplinary team of professionals, including a psychiatrist or nurse practitioner, nurse, occupational therapist, licensed clinical counselors, and an employment specialist, to deliver the interventions.

Using a family-aided assertive community treatment model,²² the team provided proactive outreach and treatment. The same care was provided to both the higher-risk group and the early first-episode psychosis group.

Each family in treatment was assigned a primary clinician and offered the following interventions:

- *Case management*, in which a clinician followed clients closely and connected them with needed services, such as housing and health and social service benefits
- *Psychoeducational multifamily group*. This key component of the intervention emphasizes skill building and strategies for avoiding psychosis and coping with the challenges of the high-risk state, for both family members and the affected youth.
- *Supportive counseling*, a therapeutic approach aimed at facilitating optimal adjustment, especially in situations of ongoing stress
- All treatment families were strongly encouraged to attend multifamily groups, while the intensity of other treatment interventions depended on the client's level of functioning and symptom acuity.

For more information on this intervention, see "Family Psychoeducation in Clinical High Risk and First-Episode Psychosis" in *Adolescent Psychiatry* (April 2012).²³

- *Supported education and employment*. An educational and employment specialist collaborated with counselors and selected teachers at schools and colleges to facilitate informal accommodations or individualized education plans when needed. This specialist also worked individually with clients to help them enhance their skills. An occupational therapist evaluated the student's functional and cognitive abilities and impairments and used the information to guide interventions.

²¹ For more details about the research design, see McFarlane WR, Cook WL, Downing D, et al. "Early Detection, Intervention, and Prevention of Psychosis Program: Rationale, Design, and Sample Description." *Adolescent Psychiatry*. 2(2): 112–124. 2012. Abstract available online.

²² Family-aided assertive community treatment is based on the idea that family involvement is a necessary component of psychosis prevention.

²³ McFarlane WR, Lynch S, and Melton R. "Family Psychoeducation in Clinical High Risk and First-Episode Psychosis." *Adolescent Psychiatry*. 2(2): 182–194. 2012. Summary available online.

The occupational therapist and the employment specialist also collaborated to support clients with jobs.

- *Medication management*, based on individual needs, to minimize the most extreme symptoms.

In Adolescent Psychiatry,²⁴ a parent describes the impact on her son of the EDIPPP protocol of weekly individual meetings, bi-weekly groups for the family, follow-up appointments, progress reports, and nurse appointments to adjust medication. "It was intense. But hearing others' experiences with their families of years of hit-or-miss treatment, long waits, and one treatment provider not communicating with the other, we were sure PIER had it right. This issue of mental illness takes a sure and steady hand and patience."

Treatment Results

The program researchers reported these results of the research study in an article in *Schizophrenia Bulletin* published online July 26, 2014:²⁵

- Family-aided assertive community treatment was more effective in managing positive symptoms among both the higher-risk and early first-episode psychosis groups, compared to the community care received by the lower-risk group.
- Negative symptoms decreased in the higher-risk and early first-episode psychosis groups, compared with the lower-risk group.
- Rates of conversion to psychosis (6.3 percent in the higher-risk group, compared to 2.3 percent in the lower-risk group) and first negative event did not differ significantly. The proportion of conversions was lower than expected, compared to prior studies (6.3% vs. 29%—a 78% reduction in risk).
- In the group receiving treatment, participation in work or school was at 83 percent at baseline and remained the same 24 months later. Participation among the lower-risk group fell from 84 percent to 79 percent in that time frame.

Impact of the EDIPPP Program on Psychosis Incidence Rates

The program team continues to analyze the data about hospitalization rates for psychotic episodes in the EDIPPP communities. Early findings suggest that hospitalization rates for

²⁴ See Migliorati M et al., page 9 of this report.

²⁵ McFarlane WR, Levin B, Travis L, et al. "Clinical and Functional Outcomes After 2 Years in the Early Detection and Intervention for the Prevention of Psychosis Multisite Effectiveness Trial." *Schizophrenia Bulletin*. First published online July 26, 2014. doi: 10.1093/schbul/sbu108.

at-risk young people were down in all of the sites where data was available. See Afterward for more information.

In an article in the October 2014 issue of *Psychiatric Services*²⁶, the researchers reported:

- The rate of first hospital admission for psychosis decreased significantly by 26 percent in the Greater Portland area compared to an 8 percent increase in the control areas. Taking into account the increase in the control areas, the actual percentage reduction in Greater Portland during the intervention period was 34 percent (24 percent plus 8 percent). The reduction in admissions was largest for individuals with nonaffective nonschizophrenic psychosis.²⁷

The authors concluded that “PIER has demonstrated that population-wide early identification is feasible.

Preventive intervention can reduce rates of initial hospitalizations for psychosis in a midsized city.”

Sustaining and Expanding the Effort

- **California and Oregon are incorporating early identification and intervention for psychosis into mental health systems statewide. The EDIPPP teams are playing a key role in the launch of the programs.**

— **California.** The EDAPT program secured a three-year \$1.92 million renewable contract from the county of Sacramento through the Prevention and Early Intervention program of the Sacramento County Mental Health Services Act.²⁸ The name was changed from EDAPT to SacEDAPT to reflect the new funding.

The county funds allowed the program to maintain its current services and also to hire a peer counselor, clinic coordinator, and second supported education/employment specialist to further expand its prevention and early intervention services.

The program will implement the EDIPPP model in a sample of 120 families in the county of Sacramento who are either experiencing early signs of psychosis, or are early in their first episode of psychosis. The SacEDAPT team is training people in

²⁶ McFarlane WR, Susser E, McCleary R, Verdi M, Lynch S, Williams D, and McKeague IW. “Reduction in Incidence of Hospitalizations for Psychotic Episodes through Early Identification and Intervention.” *Psychiatric Services*. 65(10). October 2014. First published March 17, 2014. Abstract available online.

²⁷ Nonaffective nonschizophrenic psychosis refers to psychoses not related to emotions or moods or to diagnosis of schizophrenia.

²⁸ The Mental Health Services Act, also known as Proposition 63, established a 1 percent tax on personal income in excess of \$1 million, with 15 percent of the funds used to support early intervention and prevention programs. This includes outreach to help professionals and families recognize early signs of potentially disabling mental illness and direct those in need to appropriate care.

two small counties near Sacramento to provide community outreach and early intervention services.

For more details, see the case study “California’s Approach to Early Intervention and Prevention of Psychosis” on the RWJF website.

MacFarlane also notes that, “The team from Portland, Maine, trained people in five large counties in California to closely replicate the PIER model, using training methods used earlier in EDIPPP. The five counties have had the same results as the sites in EDIPPP. “

- **Oregon.** In 2007, the Oregon legislature funded statewide dissemination to bring the most current, evidence-based treatment to teens and young adults in the early stages of psychosis. The Early Assessment and Support Team (EAST) received \$2.175 million in state funding for clinical services and to provide technical assistance to other sites. EAST also received \$50,000 from Spirit Mountain Community Fund and \$150,000 from the Paul G. Allen Family Foundation.

Early psychosis programs are now available in 19 counties covering 81 percent of Oregon’s population. Planning and implementation are underway to make them available to everyone by the end of 2014.

“We have gotten a lot of legislative traction,” Roderick Calkins, PhD, EAST’s director, said at the March 2013 meeting of EDIPPP sites in Washington. Calkins noted that both the cost-benefit analysis and the human dimensions of the issue resonate with legislators. “Health reform is continuing in Oregon, and EAST is often held up as the desirable outcome in terms of what prevention and care ought to be.”

The Oregon Department of Human Services Vocational Rehabilitation Division provided some \$126,000 for vocational supports to adolescents and young adults. These funds were used to pay for EAST’s activities outside Marion County and to supplement the Marion County budget for services not funded by RWJF.

“These additional funds plus local mental health agency contributions, insurance billing and another projected \$120,000 per year anticipated from the state next fiscal year have laid the groundwork for EAST’s sustainability at a level of intensity similar to what we have achieved through EDIPPP,” the team reported to RWJF.

For details, see the case study “Oregon’s Approach to Early Intervention and Prevention of Psychosis” on the RWJF website.

- **Two sites have integrated early identification and treatment into hospital and agency systems of care.**
- **Michigan.** Early intervention is now an integral part of the Youth and Family Services continuum of care and is available to Medicaid recipients in Washtenaw

County, the team reported. The team continues to facilitate multifamily groups for youth and their families affected by psychosis or a mood disorder with similar symptoms. They also continue to provide ongoing community outreach and education.

Because of the local expertise developed around high-risk assessments, the team developed a clinical evaluation unit in the University of Michigan Department of Psychiatry, which provides assessment, referral, and treatment for individuals identified as being at risk. The High Risk Evaluation Clinic is run by Stephan Taylor, MD, EDIPPP's principal investigator, and Liwei Hua, MD, a board-certified child psychiatrist.

Several graduate students who have worked with the M3P program are pursuing further training focused on youth at risk for serious mental illness.

- *New York.* RAP (Recognition and Prevention) has incorporated family-focused treatment, including multifamily groups, into the Zucker Hillside hospital's Outpatient Child and Adolescent Psychiatry Department. The team is preparing articles related to neurocognition and social and role functioning as a result of EDIPPP.

- **Two sites are participating in or have proposed research projects that support the work of early intervention.**

- *Maine.* The PIER Program in Portland has received a grant through Columbia University to look at the role of stigma in early intervention. PIER started outreach and recruitment for this study in December 2012.
- *New Mexico.* The Department of Psychiatry at the University of New Mexico Health Sciences Center continues to participate in the Early Treatment Program, part of the RAISE Project, a large-scale research project funded by the National Institute of Mental Health.

In the Early Treatment Program, a person receives treatment soon after experiencing the early signs of schizophrenia. One of the treatments being studied, NAVIGATE, is a comprehensive team-based treatment approach that helps individuals and their family members or other supportive people negotiate the road to recovering from the symptoms and experiences that can be typical of schizophrenia.

- **In 2014 the states of Maine and New Mexico were each awarded \$1 million grants through the federal Substance Abuse and Mental Health Services Administration (SAMHSA) to participate in a new early intervention program.** Called "Now is the Time Healthy Transitions: Improving Life Trajectories for Youth and Young Adults with, or at Risk for, Serious Mental Health Conditions," the program aims to improve access to treatment and support services for youth and

young adults ages 16 to 25 who either have, or are at risk of developing, a serious mental health condition.

- **The State of Maine received a separate five-year, \$5 million grant from SAMHSA to develop early intervention services in two large areas of the state.**

In addition, the remaining staff members at the national program office are submitting an application to re-create the PIER Program in Southern Maine, in collaboration with Maine Behavioral Health, the mental health division of MaineHealth, the parent organization for Maine Medical Center.

- **The state of Delaware (not involved in EDIPPP) also received a SAMHSA grant and plans to implement the PIER model as its early intervention program, McFarlane said.**

Communications Results

The staff of the national program office worked with Worldways Social Marketing early in the program on a strategic communications plan, talking points, media kits, and creation of a website. In 2011, RWJF contracted with Burness Communications for strategic communications assistance. Burness produced an array of issue briefs and case studies and helped staff plan the program's March 2013 policy-focused meeting in Washington.

PIER staff hosted a day-long statewide conference on May 12, 2014 in Augusta, Maine to deliver research results and train school-based and mental health professionals. Entitled "Identifying Early Signs of Psychotic Illnesses: What Every Community and School Based Practitioner Needs to Know," the conference drew some 140 people.

Adolescent Psychiatry Special Issue

Adolescent Psychiatry invited national program and project site staff to submit articles on early intervention with psychosis for a special issue, published in April 2012.²⁹

Websites

The program created two websites (www.preventmentalillness.org and www.changemymind.org) to provide an overview of the program and to guide referrals to accurate information about psychosis and early intervention.³⁰ As of October 2014, the program was gathering materials for a "clearinghouse website" to disseminate information developed over the course of the EDIPPP study.

Materials in the clearinghouse will include links to key research publications to date, summaries of outcomes from PIER and EDIPPP studies; links to all programs providing

²⁹ *Adolescent Psychiatry*. 2(2). April 2012. Contents and links available online.

³⁰ Changemymind.org is now a page on the RWJF website. Preventmentalillness.org is no longer active.

first episode and ultra-high-risk-for-psychosis services nationwide; videos developed by RWJF on EDIPPP; early intervention, reports, issue briefs, educational handouts and tools developed for professionals from the two websites; and a sign up system for a listserv for people interested in ongoing dialog and updates about early intervention in mental illness. The National Association of State Health Program Directors will host the clearinghouse website, which is expected to go live in early 2015.

Videos

The program produced three videos that describe various aspects of the program:

- “PIER Program: Portland Identification and Early Referral” (April 9, 2009). An overview of the PIER program in Portland, Maine, with commentary from McFarlane, Lynch, PIER staff, and clients of PIER and their parents
- “Schizophrenia Prevention and Early Psychosis Treatment” (May 8, 2012). Teens and families in the PIER program talk about the early signs of psychosis and schizophrenia and experts discuss how new treatment plans are preventing schizophrenia; includes an overview of the Maine Medical Center.
- “Preventing the Onset of Severe Mental Illness: Lessons Learned” (May 6, 2013). An overview of the EDIPPP, with commentary from RWJF’s Lowe, EDIPPP’s McFarlane and Lynch, and PIER client Tiffany Martinez

Media Coverage

Time magazine’s annual prevention issue, published June 12, 2009, included six pages on preventing mental illness. Interviews with McFarlane and PIER staffer Patti White are a prominent part of the article.³¹

National Council Magazine, the quarterly publication from the National Council for Community Behavioral Healthcare, included articles about EDIPPP in its Spring 2009 issue.

The PIER model was also featured in “Halting Schizophrenia Before It Starts,” an October 20, 2014 segment on National Public Radio, available online.³²

³¹ Cloud J. “Staying Sane May Be Easier Than You Think.” *Time*, 173(24), June 22, 2009. Available online.

³² Standen Amy. “Halting Schizophrenia Before It Starts.” National Public Radio. Oct. 20, 2014. Available online.

SIGNIFICANCE OF THE PROGRAM

EDIPPP has contributed significantly to the new characterization of a high-risk state for psychosis that includes the pre-psychotic phase, McFarlane said. He cites the recent review of the field in the January 2013 issue of *JAMA Psychiatry*. The article notes that:

*The...research...has the potential to shed light on the development of major psychotic disorders and to alter their course. It also provides a rationale for service provision... and the possibility of changing trajectories for those with vulnerability to psychotic illnesses.*³³

Expanding scientific understanding can “change the trajectories” of mental illnesses, as it has with other chronic illnesses, RWJF’s Lowe and the program’s McFarlane assert.

“What drove us to understand more about cancer and heart disease was the basic science,” McFarlane said. “When we were able to understand the science of tumor development and the immunology system, then we were able to target drug and radiation therapy in ways that gave you huge advances in the treatment of cancer.

“I think as we start to understand the biological basis of mental illness, we will be able to make advances in prevention, because we will be able to intervene early, so that changes in the brain don’t take hold.” RWJF’s Lowe added, “We can minimize the damage to the brain and thereby the damage to people’s functioning and keep them in a healthier, better place.”

LESSONS LEARNED

Outreach

1. **Create diverse community steering councils to help with outreach.** The sites said councils provided invaluable guidance on how best to approach outreach within academic, medical, mental health, and culturally diverse community groups. “The diversity of our steering committee ensured that we would have ‘buy in’ from key stakeholder communities,” the California team reported. “In particular, having representatives from the Sacramento City Unified School District, the Sacramento County Mental Health Services, and consumer advocate representatives on our steering committee was invaluable.” (California report to RWJF)
2. **In outreach to schools, make sure to engage the special education or special services directors.** “They are very powerful, usually second in command to the superintendent,” says Portland, Maine, school social worker Cynthia Wilcox. “The

³³ Fusar-Poli P, Borgwardt S, Bechdolf A, et al. “The Psychosis High-Risk State.” *Journal of the American Medical Association Psychiatry*. 70(1): 107–120. 2013. Abstract available online.

superintendent listens to their opinions about anything to do with mental health. In our district we were blessed with a director that totally supported the PIER program and that worked really well. She fostered a climate where we were accepted and encouraged to make referrals to PIER.”

3. **Realize that bureaucracy may be a barrier to outreach in large school systems.** The New York City school system had many rules about involvement of outside agencies, the New York EDIPPP team discovered, and was particularly resistant to providing access to research projects. “Over time, we did develop strategies to help deal with many of the access restrictions,” the team reported to RWJF. “However, although referrals to the program substantially increased, patient enrollment was not similarly improved.”
4. **Look for the most efficient way to educate an entire school system, rather than depending solely on the connections made with individual schools.** “Most states have school health conferences and most of the professionals working in schools either in health or mental health go to those meetings,” McFarlane said, “so you could start the education process there for a whole state or a whole school system.” Such a process worked well in Portland, he said. “We had the entire professional staff in the room for a couple of hours and that got us started.”
5. **The smaller the catchment area, the quicker the outreach to schools.** For example, sites with only one or two school districts were able to reach schools more efficiently compared to sites that had to deal with multiple districts, the evaluators reported. (Evaluation report, 2010)
6. **Be clear about the expectations for outreach activities.** Sites were given flexibility in how they did outreach, which led to some confusion about expectations, said lead evaluator Joly. “They did not know they were to do outreach with all the schools,” she said, “and they did not know they were expected to have 12 outreach activities per month. In year one, we worked with the national program office to clarify for the sites what those expectations were. That helped us with our evaluation.”
7. **Program staff must carefully balance the time they spend on outreach and their clinical work.** “In order to identify and recruit clients, there is a need for significant community outreach activities,” the national program office staff reported. “However, if outreach has been successful and leads to an influx of referrals and enrollments, those doing outreach (clinicians) must shift their time and effort on to clinical work.” (Report to RWJF)
8. **Designate an outreach coordinator to assist with the scheduling and logistics of outreach presentations.** “Outreach coordinators played a critical role in planning, providing, and tracking training efforts and other activities designed to increase program awareness and generate referrals,” the evaluation team reported. “The selection of an outreach coordinator is critical to success.” (Evaluation report, 2010)

9. **Provide training about outreach strategies both early in the program and midway through.** Staff at the sites received outreach training early in the grant cycle at the same time they were trained on the clinical component and grant requirements. "A mid-grant outreach training session would have likely been useful," the evaluators reported, "as well as ongoing communication with the principal investigators about the value of outreach and their sites' progress." (Evaluation report, 2010)

Evaluation

10. **Begin the evaluation at the beginning of the research project.** The EAST team in Oregon did extensive outreach in the months before the evaluation team officially began to collect data. "It would have been more reflective of the actual effort if the evaluation had been implemented simultaneously with the start-up of EDIPPP," the Oregon team reported to RWJF, "since it resulted in the absence of more than 2,000 individuals who received presentations prior to the beginning of data collection."
11. **Continue to fine-tune data collection, when possible, to capture the level of detail needed for the evaluation.** For example, the outreach data indicated that a high percentage of parents contacted the program, but not where those parents first heard about it. "Parents did not come to us directly," EDIPPP's Lynch said. "They came through a provider. The outreach evaluation does not tell us certain information... It does not tell us how effective our outreach was, or who, really, were the referrers."

The evaluation team also had to clarify some of its definitions to ensure consistency. A year into the project, the evaluators learned that one of the sites was recording all of its informal outreach as "formal presentations." "We clarified the definitions of formal versus informal presentations and embedded those changes to the protocol for data collection," said evaluator Joly.

Referral and Intervention

12. **Designate one staff person in a school who will refer at-risk students once they are identified.** "The referral process needs to be clear," Portland, Maine, school social worker Wilcox said. "There was muddiness in the beginning, but then we got together and said, 'Let's just have the social worker do it in each school.' That worked out best. It doesn't have to be the social worker, but in all the schools I am aware of, the school social worker was the liaison person with the program."
13. **Work patiently to engage parents of young people being referred to the program.** "It was a little challenging at times to get the parents on board when a referral is needed," Wilcox said. "Most of them have not had experience with mental illness, or if they have, it hasn't been accurately diagnosed and treated. ... It is frightening when someone starts to put a name to it ... They are afraid of stigma, sometimes, afraid of what they didn't understand."

In Portland, the schools overcame these barriers by pulling in PIER staff and school staff, as needed, to talk with parents. "Parents may not know me," Wilcox said, "but

they know the teachers.... I can't think of any situation in our school district where we couldn't eventually get a child in there. It takes patience and support of the parents."

14. **Provide training and supports so that practitioners are equipped to follow all components of the intervention model.** While the sites received intensive training in leading multifamily psychoeducation groups, there was no training for delivering supportive counseling and no assurance that people from different disciplines were following the same protocol. "We know how much counseling people got but we don't know how effective it was," said Lynch. "I would have liked that to be more structured."
15. **Monthly check-in calls were essential to retaining subjects in the research.** "These calls, although requiring sustained staff effort for completing and tracking them, kept us in close contact with almost all participants, including the control participants whom we did not engage in treatment," the New York team reported. "Our research assessment completion rates at the 24-month time point (91 percent) demonstrate this."
16. **Be flexible and attentive to cultural barriers as treatment services are delivered.** The California team encountered resistance to multifamily groups among participants of Asian descent. The team found that many of the families from the Asian and Pacific Islander communities in the Sacramento area, were resistant to the idea of discussing mental health problems in front of other Asian Pacific Islander families (due, for example, to concerns about saving face)." In coordination with the national program office, the team addressed this problem by making single-family interventions available.

The New York team also found that providing individual family problem-solving sessions was useful in engaging families who were resistant to the multifamily group format. "This allowed for all families to receive treatment with optimum support," the team reported.
17. **Be prepared to provide extensive case management services to families.** The New York team reported that a number of families in the study were experiencing significant personal and financial difficulties and required significant support, which they provided through case management.

Sustaining Early Intervention Programs

18. **In order to sustain the program, staff must start early to expand their personal and organizational knowledge of health care financing.** "We did not anticipate the difficulties we would face in transitioning this clinical research program to a clinical program," PIER staff reported to RWJF. "The issues around staff credentialing, billing, registration, and finances have been complicated and, at times, unwieldy." While the program began work on sustainability a full two years prior to the end of the site grants, that was not early enough, the staff reported.

19. **Consider how an early intervention program fits best within routine business operations.** The M3P program in Michigan initially kept financial procedures and electronic medical records separate from those used by their parent organization. Although they intended that approach to be part of a long-term sustainability plan, “we quickly learned that being part of the existing operational structure was the most efficient, cost effective, and sustainable way to function,” wrote project staff in a report to RWJF.
20. **Figure out how to bill for services while participating in a research study.** With the end of RWJF and National Institute of Mental Health funding, most of the PIER program is no longer funded through the Maine Medical Center, which is a loss for the community, Lynch said. “I wish we had had the research study going on at the same time as we were billing for first episode clients. We would have had a better chance of staying open as a program if we had been doing both research and billing.”

AFTERWARD

Examining Incidence Outcomes

The program team and research consultants continue to analyze data on the incidence of hospitalizations from the EDIPPP demonstration. Preliminary data suggest that first hospitalizations for psychosis among the target age group have gone down in the five EDIPPP demonstration catchment areas. However, in two of the sites, hospitalizations across the control catchment area had also gone down.

“The question is what was happening?” McFarlane said. “That is much more complicated. We are still working on that piece, and I think that is important.”

One of the areas that saw a reduction in hospitalizations was Brooklyn, N.Y., with a population of 2.5 million. “The level of hospitalization for first psychosis was going down prior to the start of EDIPPP,” McFarlane said. “I think that is because there has been a population shift in Brooklyn [with] a ton of young middle-class families whose kids are not in the age at risk [moving in]. Further, some hospitals in Brooklyn have been closed to admissions, while beds available for adolescents have decreased.”

McFarlane questions whether the results are conclusive, since the control areas had very inconsistent trends: “The test sites all had decreases in incidence, but the control area problem makes conclusions on effects of the EDIPPP sites somewhat ambiguous.” Instead, he says he’s been using a “graphical representation... in verbal presentations with caveats.”

Sustainability and Policy Implications

Sustainability of early identification and intervention programs depends on their becoming part of the educational and mental health systems of communities, McFarlane

asserts. That premise is being put to the test in California, where a special fund for mental health services is supporting early intervention statewide, and in Oregon, where early intervention is being rolled out as part of county-run mental health systems (see *Sustaining and Expanding the Effort*).

Two provisions of the federal Affordable Care Act also may be policy drivers:

- The funding of prevention initiatives
- The option for parents to include their children age 26 and younger on their health insurance policies

McFarlane believes insurers may be interested in providing early identification and intervention for these young adults.

“I hope we will be able to see some pickup on this idea of early detection,” Lowe said. “We know now that you can identify correctly these young people, and if you can identify them and get them into care, we know that you can improve their lifelong outcomes for health.

“The critical piece is how do we convince policy-makers and insurers that this is something worth putting some resources into,” she continued. “That is really where I would see the hope for sustainability.”

Further RWJF Work in Mental Health

RWJF is also interested in ways it could inform public policy in the mental health realm. “We are looking for opportunities to promote what we learned about early identification, treatment, and prevention, and work with the Substance Abuse and Mental Health Services Administration to get that adopted more widely,” Lowe said.

RWJF is funding projects focused on social and emotional learning³⁴ for children in elementary schools, middle schools, and secondary schools.³⁵ “We will continue to explore what kinds of things we need in school-based mental health,” Lowe said, “and whether we can link it better to community-based mental health.”

³⁴ Social and emotional learning (SEL) is a process for helping children and adults develop the fundamental skills for life effectiveness. SEL teaches the skills one needs to handle oneself, one's relationships, and one's work both effectively and ethically. (“Background on Social and Emotional Learning.” *CASEL Briefs*, December 2007).

³⁵ Grant ID# 69869. Developing Approaches for Effective Adoption and Long-Term Sustainability of Programs and Practices that Advance Social and Emotional Learning. \$1,496,603 (May 1, 2012 to April 30, 2014); Grant ID# 70029. Scaling Up and Building Systemic Support for Social and Emotional Learning in School Districts Nationwide. \$496,202 (July 1, 2012 to April 30, 2014); and Grant ID# 70985. Conducting Cost-Benefit Analyses of Social and Emotional Learning Programs. \$199,967 (July 1, 2013 to June 30, 2015).

In December 2013, RWJF funded a project called Beacon of Health: Using mobile technology to detect early warning signs of mental health challenges and enhance treatment delivery for youth.³⁶ The University of California, Davis, Medical Center is testing the use of a unique mobile phone platform for collecting real time, self-report, and sensor information for managing and intervening with youth at risk of psychosis.

It is a collaboration of the expertise of UC Davis's EDIPP program with the expertise of Ginger.io, a behavioral analytics company that uses machine learning and data mining to passively collect and analyze subtle signals of behavior change to better understand users' social, physical, and mental health status. This data-driven approach has the potential to change health care delivery for this population by accurately informing treatment providers of patient status, assessing real-time treatment response, and prompting patients and providers to engage in relapse prevention strategies when needed. Results will be communicated through research conferences, peer-reviewed publications, and presentations for other community mental health providers.

The Foundation is also exploring the area of Adverse Childhood Experience (ACES) and how they affect mental and physical health later in life.

³⁶ ID# 71391 (\$588,619, December 14, 2013 to February 14, 2015)

Sidebar

BACK FROM THE EDGE: TIFFANY MARTINEZ

Tiffany Martinez was at college when she began to notice her mind “playing tricks” on her—and was lucky enough to get help from the PIER program

In 2005, Tiffany Martinez graduated near the top of her class in high school. Then, as a freshman at University of Southern Maine, she seemed to hit a wall.

“My mind was playing tricks on me,” she recalls. “I was seeing shadows, and then I would hear things—not loud, but they were there. It was really scary.

“Doing harmful things to myself was on my mind,” she says. “I didn’t want to verbalize it at first. It was embarrassing.”

The symptoms became more intrusive. Soon, it was hard for Martinez to leave her dorm room. If she did manage to leave, she often thought that the tall trees in the courtyard outside were going to fall on her. Worried about her welfare, her aunt and several of Martinez’s friends from school convinced her to go to the university health center.

The school nurse who met with Martinez had just attended a seminar conducted by a staff member of the Portland Identification and Early Referral (PIER) program at the Maine Medical Center. There, she had learned about early signs of psychosis—seeing or hearing things that are not there; persistent thoughts that do not go away after receiving logical or accurate information; and other cognitive and sensory changes, such as not being able to think straight, focus, or speak coherently and being overly sensitive to sensory input.

Martinez had many of the signs, so the nurse referred her to PIER for evaluation.

“People who don’t know anything about psychosis wouldn’t necessarily know these early symptoms,” says Sarah Lynch, MSW, who evaluated Martinez and admitted her to the PIER program. “What parents would see is a young person shutting down and withdrawing. Maybe he seems depressed or they are frustrated because he is not doing anything they ask him to do. They might see a change of behavior, and they’re not sure if it’s teenage rebellion.

“Even for clinicians, they learn a lot in our trainings about how subtle the symptoms can be, and what questions to ask, and the way to ask the questions,” she says.

At PIER, Martinez entered into a comprehensive program of treatment, counseling, and psychoeducational support. Because she was at college, and had few relatives nearby, family therapy was not part of her treatment plan. She met with psychiatrist James Maier, MD, who prescribed medication that helped her manage the symptoms. And she met regularly with Lynch, who helped her learn ways to control the stress that exacerbated her symptoms and encouraged her to reengage with her life.

“She was reinforcing anything good that I had been doing,” Martinez says, “and encouraging me to get back into things I had done before, like exercise and movement, and trying to be more social and not so isolated. Problem-solving skills were the big thing.”

The road back from the edge was not easy, Martinez says. “If you’re having severe paranoia, it is hard to trust and attend and show up,” she says. “I remember Sarah had to come pick me up at school, because I wouldn’t want to leave campus. I was too afraid.”

Martinez has progressed in what she calls “baby steps.” “I still have issues with adherence and going to therapy and just dealing with mental health in general,” she admits. “But I did feel constantly supported. I never felt judged. When you’re afraid to expose yourself—to be able to say those things without feeling judged is huge.”

Turning the Corner Back to Herself

For Martinez, early intervention has helped her turn the corner. After two years in the PIER program, Martinez’s symptoms had subsided and she understood the steps to take if they arose again. She finished college and, in 2011, enrolled in the master of nursing program at University of Southern Maine. She is studying to be a family psychiatric mental health nurse practitioner—a natural progression, she says. “All my experiences and the things I got interested in along the way have led me to this point. It sort of unfolded.”

Martinez also has become an advocate for early intervention. She shared her story at a national meeting of EDIPPP in March 2013 and returned to Washington in May to participate in an advocacy day sponsored by the American Academy of Child and Adolescent Psychiatry. In February 2014, she also testified before the Senate Health Education Labor & Pensions Committee in support of early psychosis intervention services. Read her testimony [online](#).

Her experiences give a human face to mounting evidence suggesting that the worst effects of psychosis can be averted with proper treatment. “When you develop schizophrenia, you drive off a cliff,” McFarlane says. “So imagine you could stop the process already underway. You’re driving down the road toward a psychotic episode, and you either drive off the cliff or you don’t.”

“We are really redefining mental illness to include its onset stage the same way we have done with cancer and heart disease,” McFarlane says. “If someone has angina, would you wait to provide services for their illness? No. Now we know that angina is the possible lead up, but not always, to a major heart attack. We will have to get there with mental illness.”

A SCHOOL SOCIAL WORKER’S PROFESSIONAL AND PERSONAL STORY

Cynthia Wilcox learned the importance of early intervention with psychosis—both as a school social worker and as the mother of a son who has struggled with mental illness.

As a social worker at a middle school near Portland Maine, Cynthia Wilcox, LCSW, has long clinical experience helping young people with an array of needs, from anxiety to learning problems. But she knew little about a cluster of symptoms that may signal early psychosis until she attended a district-wide workshop for all school health and mental health practitioners in the fall of 2004.

There, an occupational therapist with the PIER program at Maine Medical Center, spelled out subtle symptoms that may be mistaken for other issues: being fearful for no good reason; jumbled thoughts and confusion; feeling “something’s not quite right”; declining interest in people, activities, and self-care; hearing sounds or voices that are not there; trouble speaking clearly and not understanding others; and declining mental acuity, memory, or attention.

“We realized that we did not know as much as we could have known to be effective with the children,” Wilcox said. “PIER clarified so much for us about what you can look for early on.”

The workshop was part of PIER’s community outreach program aimed at identifying young people with early, or prodromal, symptoms of psychosis, and getting them into treatment designed to prevent a full-blown psychotic episode.

After the workshop, Wilcox and her colleagues in the school system began making referrals to PIER. Those young people assessed as being at risk of psychosis entered an intensive program of family psychoeducation, supportive counseling, employment and educational counseling, and medication management, as needed.

“It was incredibly refreshing to have someone come and say, ‘We want to help your students. Please refer to us,’” Wilcox said. “That had never happened with any kind of resources I can remember in all my years of social work. That’s what made it so unique. It filled this really big gap.”

A Frightening Phone Call

Psychotic symptoms often make their first appearance in teenagers or young adults. Estimates suggest that from 1 to 3 people in 100 will experience psychotic illness, which takes a tremendous toll on those who suffer from it and their families. Youth often have a hard time maintaining friendships and staying in school or on the job, short-circuiting their progress toward productive, healthy adulthood. And families face increased stress as they attempt to care for and get help for an ill son or daughter.

This reality came home for Wilcox in 2008, when she and her husband got a call from the dean of the college that their youngest son, Joe, attended. He was in a hospital emergency room, they were told, after displaying bizarre and potentially self-injurious behavior. "We were told to come right away," Wilcox recalled. "I can't think of another time in my life that I was as frightened."

After two weeks in the hospital, Joe had made some progress, but it was clear he was not ready to be back in school and needed to be in treatment. "We were going back to Portland so I thought, 'Hmm, what is available?'" Wilcox said. "I thought of PIER."

Though she had talked to PIER staff before on behalf of students at her school, making the call for much more personal reasons was difficult. "I was embarrassed and emotional," she said. "They were wonderful and asked all the questions they would have asked me if I was a social worker referring a student."

Her son was assessed and admitted to the program, and "at that point our whole family became part of the PIER program," Wilcox said.

A primary treatment intervention at PIER is family psychoeducation that focuses in particular on the emotional aspects of the family interaction. Every two weeks, in the early evening, Joe and his parents, and sometimes his siblings, attended a group with seven other families that had a family member dealing with pre-psychotic or psychotic symptoms. With the guidance of group leaders from PIER, the families solved problems together, practiced communication skills, and learned strategies for coping with symptoms.

Being with other families helped her maintain her balance and move forward, Wilcox said. "The support I got from the other parents was such a comfort. It made me realize we were not alone as we were going through this really heart wrenching time. These things can happen to other good parents and their kids."

Participating in the family group also helped Wilcox and her husband and son have more productive interactions at home. "It gave us food for thought," she said. "We could go home and have conversations with our child that might not have happened without the preparation in the group."

Keep It Simple

A key message PIER staff delivered was to “go slow and keep things simple,” Wilcox said. “That was hard for a lot of us parents, because we were all so wrought up about things. ... I loved the way they focused on the strengths of the family and the strengths of the young people, in particular. We looked forward to these meetings. It was a constant for us, at a time when there were a lot of uncertainties and fears.”

Joe’s big concern, his parents learned, was falling behind in school. PIER staff stepped in to address this by, first, helping him find volunteer work and then, as his symptoms stabilized, helping him sign up for courses at the local college. “They really advocated for him and for the other patients in the community,” Wilcox said. “What stood out for us was how helpful it was to attend to these concrete things, because it was those things that gave the kids a sense of hope and a sense of moving forward.”

Today, Joe is a college graduate and living and working independently. “It is still a long road for him and for us,” Wilcox said. “He is not out of the woods, but he is doing well right now. Had Joe not been recognized by his school and treated by PIER, I feel he would not be where he is today.”

Her family’s personal experience has brought home to Wilcox the importance of educating school personnel and others who work with young people about early signs of psychosis. “As a parent, when a kid starts to do different things, it is very easy to write it off as adolescent behavior or that he is just acting like his peers,” she said. “That is why it is so important that schools know what they are doing.”

Recent tragedies such as the shootings in Newtown, Conn., underscore the importance of early detection and intervention with serious mental illness, Wilcox believes. “If those young people had been recognized and attended to in middle school,” she said, “I feel in my heart, that some of those situations could have been avoided.”

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APPENDIX 1

Expert Committees

(Current as of the time of the grant; provided by the grantee organization; not verified by RWJF.)

Scientific Advisory Committee

The scientific advisory committee has experts in the following areas:

Methods and Statistical Analysis

Phillip Lavori, PhD

Chair, Department of Health Research and Policy
Stanford University
Stanford, Calif.

Pharmacological Intervention

Scott Woods, MD

Professor of Psychiatry
Associate Professor of Diagnostic Radiology
Prevention through Risk Identification,
Management & Education Research Clinic
Yale University School of Medicine
New Haven, Conn.

Prevention Methodology

Sheppard Kellam, MD

Founder
Center for Integrating Education and
Prevention Research in Schools
Pasadena, Md.

Mood Disorders

William Beardslee, MD

Director, Baer Prevention Initiatives
Boston Children's Hospital
Boston, Mass.

Economics and Cost Analysis

Richard Frank, PhD

Margaret T. Morris Professor of Health Economics
Department of Health Care Policy
Harvard Medical School
Boston, Mass.

Intake Assessment for Prodromal Syndrome

Thomas McGlashan, MD

Professor Emeritus of and Senior Research Scientist in Psychiatry
Yale University School of Medicine
New Haven, Conn.

Cognitive Intervention

Kim Mueser, PhD

Executive Director, Center for Psychiatric Rehabilitation, Boston University
NH-Dartmouth Psychiatric Research Center
Boston, Mass.
Professor, New Hampshire-Dartmouth Psychiatric Research Center
Concord, N.H.

National Advisory Committee

The national advisory committee has experts in the following areas:

Mental Health in Schools/Work with Native American Adolescents

Steven Adelsheim, MD
Director, Center for Rural and Community Behavioral Health
University of New Mexico
Albuquerque, N.M.

Adolescent Substance Abuse/Work with Minority Youths

Hoover Adger, MD
Director of Adolescent Medicine
John Hopkins University School of Medicine
East Baltimore Campus
Baltimore, M.D.

Work with Minority Adolescents and Families on Mental Health & Substance Abuse

Margarita Alegria, PhD
Professor, Harvard Medical School
Director, Center for Multicultural Mental Health Research
Cambridge Health Alliance
Somerville, Mass.

Mood Disorders

William R. Beardslee, MD
Academic Chair, Department of Psychiatry
Boston Children's Hospital
Boston, Mass.

Community Education & Funding

Crystal R. Blyler, PhD
Science Analyst
SAMHSA, CMHS
Rockville, Md.

Impact of School-Based Mental Health Services

Kimberly Eaton Hoagwood, PhD
Professor, Clinical Psychology and Psychiatry
Director of Child Services—Research Branch
Division of Mental Health Services & Policy Research
Columbia University—NYS Psychiatric Institute
New York, N.Y.

Family Interventions in Mental Illness

Dale L. Johnson, PhD
Professor Emeritus, Department of Psychology
University of Houston
Houston, Texas

Prevention Methodology

Sheppard Kellam, MD
Founding Director and Professor Emeritus
AIR Center for Integrating Education & Prevention Research in Schools
Johns Hopkins Bloomberg School of Public Health
Baltimore, Md.

Clinical and Policy Expertise on Mental Health and Addiction Services

David A. Pollack, MD
Professor for Public Policy
Oregon Health Sciences University
Portland, Ore.

APPENDIX 2

Project List

Portland Identification and Early Referral (PIER) Program at Maine Medical Center (Portland, Maine)

ID# 59639 (December 2006–August 2011) \$1,994,207

Project Director

William R. McFarlane, MD

(207) 662-2091

mcfarw@mme.org

Early Assessment and Support Team (EAST) at Mid-Valley Behavioral Care Network (Salem, Ore.)

ID# 61266 (April 2007–March 2011) \$2,000,000

Project Director

Roderick Calkins, PhD

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Michigan Prevents Prodromal Progression (M3P) Program at Washtenaw Community Health Organization (Ypsilanti, Mich.)

ID# 61265 (April 2007–March 2012) \$2,000,000

Project Director

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Recognition and Prevention (RAP) Program at Zucker Hillside Hospital (Queens, N.Y.)

ID# 61430 (May 2007–April 2012) \$1,999,484

Project Director

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Early Detection and Preventive Treatment (EDAPT) Clinic at University of California, Davis (Sacramento, Calif.)

ID# 61264 (April 2007–March 2012) \$1,999,652

Project Director

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**Early Assessment and Resource Linkage for Youth (EARLY) Program at
University of New Mexico (Albuquerque, N.M.)**

(This site received no RWJF funding.)

Project Director

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APPENDIX 3

Lessons Learned About Outreach

The evaluators described these lessons in the article “Evaluating Community Outreach Efforts: A Framework and Approach Based on a National Mental Health Demonstration Project” published in the July 2012 *Journal of MultiDisciplinary Evaluation*.³⁷

Applying Evaluation Frameworks Provides Focus

Paying careful attention to how and by whom an the evaluation is used, and using a participatory approach, was helpful in gaining support for the outreach evaluation and assuring that data collection tools were used by the sites and are useful in informing outreach activities.

The evaluators based their approach on two frameworks. The first, referred to as the Ottoson and Green framework, uses four questions to guide the evaluation of community-based outreach efforts.

- How will evaluation findings be used and by whom?
- What is outreach and what factors may affect influence outreach?
- How will the success or failure of outreach be determined?
- What methods will be used to assess the success of outreach?

The second framework, developed by the Centers for Disease Control and Prevention, identifies six steps that should be taken in any public health program evaluation: (1) engage stakeholders, (2) describe the program, (3) focus the evaluation design, (4) gather credible evidence, (5) justify conclusions, and (6) ensure use and share lessons learned.

³⁷ Joly BM, Williamson ME, Bernard NP, et al. “Evaluating Community Outreach Efforts: A Framework and Approach Based on a National Mental Health Demonstration Project.” *Journal of MultiDisciplinary Evaluation*. 8(17): 46–56. 2012. Abstract available online.

Context Matters

Given the diverse communities, staffing mix, and organizational history of the sites, the exploration of facilitating factors and impediments to outreach was essential to the evaluation. Had they not included this component in the initial design, the evaluators note they would have likely missed opportunities to understand site differences and how these differences impacted their ability to conduct outreach.

By analyzing contextual factors, the evaluators were able to identify several noteworthy areas that influenced outreach efforts, including policy changes and existing relationships with community organizations and residents.

Engagement is Important and Requires a Significant Investment

Engaging stakeholders in a participatory evaluation design will likely lead to more buy-in and use of the findings. However, the participatory evaluation process required a significant up-front time investment, including a planning period of approximately six months. The result was a delay in developing and finalizing the data collection tools and launching the online database.

Initial Resistance Can be Overcome

The evaluators experienced initial resistance from several sites about the collection of evaluation data, particularly among those who were concerned with the time commitment and not convinced of the value of the outreach evaluation. To minimize concerns and ensure participation, the evaluators:

- Assured that the data collection tools were relevant and that the information collected would be beneficial for the national evaluation and for individual sites
- Used techniques reported by other community outreach evaluators to create quantitative data collection instruments that were reliable, comprehensive, and relatively unobtrusive.
- Decreased the burden of data entry by establishing a process in which a member of the evaluation team entered participant training and instructor data into the Web-based database. This approach ensured consistency and provided a mechanism for verification.
- Generated site-specific monthly reports of outreach activities that could be used by each site for its own reporting requirements, which provided a direct incentive for grantees to collect and update the data

Developing Reliable and Realistic Methods Is Critical

Given the challenges inherent in measuring and operationalizing outreach efforts, the evaluation team quickly realized the need for a central, secure, and quality database to ensure uniformity in data collection across all sites. As part of this process they:

- Worked with a vendor to create a simple and easy to navigate Web-based interface and provided training on the database
- Incorporated elements into the design of the database that were not critical to the evaluation, but directly benefited the grantees (e.g., contact lists, grantee progress reports)
- Insured that data were disseminated in a timely manner to all sites for verification and to assist with their planning, tracking, and reporting efforts

APPENDIX 4

Characteristics of Referrers to Program

Based on a series of key informant interviews across all sites with individuals who made a referral to EDIPPP, the evaluators found that:

- **Referrers tended to be highly educated women.** Most referrers were women, and many referrers had a postgraduate degree. While some sites were limited in their ability to collect this information due to Institutional Review Board issues, the data suggest that professionals made most of the referrals, rather than family members, friends, or co-workers.
- **Referrers heard about EDIPPP primarily through a training session, staff member, or provider.** Nearly one in four individuals who made a referral first heard about the program through a training session.
- **The referrer's relationship with the client varied.** In general, referrers either had known the client they were referring for more than five years or less than one month. Unsurprisingly, professionals were significantly more likely to have been in contact with the client for less than 30 days than friends or family.
- **Professional were significantly more likely than nonprofessional referrers to have made a referral in the past and to have made an appropriate referral.**
- **The number of people making multiple referrals increased over time, particularly among professionals.** While most referrers were first-time callers, a significant subset (27%) made multiple referrals; this was an important source of clients to EDIPPP. Oregon had the highest number of multiple referrers, followed by Maine and Michigan.

APPENDIX 5

Referral and Program Completion Data for EDIPPP Sites

Portland Identification and Early Referral Program (PIER) (Maine)

Between December 2006 and June 2011, PIER program staff conducted 193 community outreach presentations, reaching 4,531 people in the Portland area. During the grant period, 63 young people were enrolled in the research study, which provided intensive treatment to some and standard treatment to others; 17 of them withdrew before the end of the study.

Early Assessment and Support Team (EAST) (Oregon)

From November 2007 through March 2011, EAST staff made 239 presentations to 4,980 individuals. There were 158 unique referents, not including family members, of young people to the program during that period.

Michigan Prevents Prodromal Progression (M3P) (Michigan)

The project team gave some 210 outreach presentations reaching 8,000 individuals—primary care providers, school staff, etc. The outreach effort covered 90 percent of the priority zip code areas. Some 55 people were evaluated, and 40 were assigned to the active treatment intervention.

Recognition and Prevention Program (RAP) (New York)

The RAP team conducted more than 120 outreach events, reaching over 4,000 individuals. They received 745 referrals; 43 patients were accepted as active participants in the EDIPPP. Twenty-three patients met criteria for the treatment condition, and 20 were assigned to the control condition.

Early Detection and Preventive Treatment (EDAPT) (California)

The EDAPT team conducted outreach in Sacramento area school districts, community colleges, and mental health agencies. Through Grand Rounds and conference presentations, staff members also introduced the initiative to pediatricians, primary care and family medicine physicians, and to mental health workers. Staff reported that 38 individuals completed the 24-month study which provided intensive treatment to some and standard treatment to others.

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